

BACKGROUND TO THE PROPOSED REGULATIONS DEFINING DEVELOPMENTAL DISABILITY AND SUBSTANTIAL HANDICAPS

AS A CONSEQUENCE OF THE PASSAGE OF THE LANTERMAN ACT, RELATED TO SERVICES FOR CITIZENS WITH DEVELOPMENTAL SPECIAL NEEDS, THE DEPARTMENT OF HEALTH HAS BEEN MANDATED TO ESTABLISH A REGULATORY DEFINITION FOR THE TERM DEVELOPMENTAL DISABILITY AND TO DEFINE SUBSTANTIAL HANDICAP. THESE TWO DEFINITIONS MAY BE CONSIDERED THE CRITICAL CONCEPTS IN THE ENTIRE FIELD OF DEVELOPMENTAL SERVICES. EACH DESCRIBES THE CRITERIA FOR WHAT MAY BE CALLED CITIZENSHIP RECOGNIZED BY FEDERAL AND STATE GOVERNMENTS UPON WHICH HINGE THE RECEIPT OF RECOGNITION, SERVICES, AND RESOURCES. WE ARE SEEKING YOUR INPUT AND RESPONSE PRIOR TO FILING THE PROPOSED REGULATIONS IN ORDER TO ASSESS, TO THE BEST DEGREE POSSIBLE, THE IMPACT ON THE DELIVERY OF DEVELOPMENTAL SERVICES TO CALIFORNIANS.

HISTORICALLY, THE CONCEPT OF DEVELOPMENTAL DISABILITY WAS ORIGINALLY CONFINED TO THOSE PEOPLE WHO COULD BE LABELED MENTALLY RETARDED, CEREBRAL PALSY, OR THOSE WHO HAD EPILEPSY. CONSEQUENTLY, THE OPERATING DEFINITION WAS INCREASED TO EMBRACE PEOPLE LABELED AUTISTIC AND THE LARGE GROUP EXPERIENCED AS DISABLED IN THEIR LEARNING BEHAVIOR. SERVICE CITIZENSHIP WAS INITIALLY DEFINED BY DIAGNOSIS; THAT IS TO SAY, THE LABELING OF CIRCUMSTANCES EXISTING WITHIN THE INDIVIDUAL. THE IMPORTANCE OF THIS ASSUMPTION CANNOT BE OVER-EMPHASIZED FOR ONCE THIS ASSUMPTION BECOMES THE FUNDAMENTAL PERSPECTIVE, A SET OF ATTITUDES, JUDGMENTS, AND SOCIAL STRUCTURES LOGICALLY AND IRREVOCABLY FOLLOW, THE JUDGMENTS ARE INVARIABLY MADE BY PROFESSIONALS WHO ARE VESTED WITH THE RESPONSIBILITY OF

DIAGNOSIS, BY IDENTIFYING THE PROBLEM IN THE INDIVIDUAL, IT WAS A SIMPLE NEXT STEP TO MAKE THE CONNECTION BETWEEN THE PROBLEM AND THE INDIVIDUAL AS A WHOLE. THIS PROCESS OF AFFIXING A LABEL BY ESTABLISHING A DIAGNOSIS THAT DESCRIBES THE "BEING" OF A PERSON CHANGES THE INDIVIDUAL'S STATUS AND HUMAN CONDITION IN THE EYES OF JUST ABOUT EVERYONE.

THIS LABELING EXERCISE REINFORCES THE BELIEF THAT THE PERSON WHO IS NOW DESCRIBED AS DEVELOPMENTALLY DISABLED, RETARDED, AUTISTIC, EPILEPTIC, CEREBRAL PALSID, OR LEARNING DISABLED, IS NOT LIKE US. WE ARE INTACT SYSTEMS. WE ARE NORMAL. "THEY" ARE NOT. THEY ARE MALFUNCTIONING SYSTEMS. THEY NEED SPECIAL EDUCATION. THEY NEED TO BE PROTECTED. THEY NEED SYMPATHY. THEY CAN NEVER MARRY. THEY CAN NEVER ENJOY A NORMAL SOCIAL LIFE. THEY CAN NEVER BE FULLY ACCEPTED BY MY FRIENDS AND STRANGERS. THEY CAN NEVER REALLY BE HAPPY, THEY SUFFER. THEY CAN NEVER KNOW WHAT IT IS LIKE TO BE FREE. THEY WILL ALWAYS BE DEPENDENT, THEY WILL DIE SOONER.

WE CAN UNDERSTAND IN RETROSPECT THE WAY IN WHICH SUCH ATTITUDES GOT TRANSLATED INTO A MATERIAL SOCIAL RESPONSE. SEGREGATED AND ISOLATED SETTINGS, CATEGORICAL FUNDING, AND CATEGORICAL SERVICE AGENCIES THAT ARE "SEPARATE BUT EQUAL", A WHOLE INDUSTRY OF PROFESSIONALS AND RESOURCES ESPECIALLY FOR LABELED PEOPLE ARE OVERT EXAMPLES OF SUCH RESPONSES.

WITHIN THE LAST DECADE, THE FAMILY VOLUNTARY ORGANIZATIONS HAVE ORGANIZED TO REASSERT THE BASIC CITIZENSHIP RIGHTS AND FUNDAMENTAL HUMANITY OF THEIR SONS AND DAUGHTERS. MORE AND MORE PROFESSIONALS HAVE BEGUN TO WAKE UP TO THE NEED TO REDEFINE AND TO RESEE THIS

CONSTITUENCY. THEY HAVE RECOGNIZED THAT TO BE HUMAN IS TO POSSESS THE INHERENT AND INALIENABLE CAPACITY TO GROW, CHANGE, AND SHARE IN THE FULL FRUITS OF WHAT WE KNOW AS OUR SOCIETY, THE NEED FOR RESPECT, POWER, RESOURCES, INTERDEPENDENCY, PRODUCTIVITY, AND THE RIGHT TO EXPERIENCE AS MORAL A LIFE AS POSSIBLE, AS A BASIC MINIMUM, HAS FOSTERED MASSIVE BREAKTHROUGHS IN EDUCATIONAL TECHNOLOGY, CIVIL RIGHTS LAW, LEGISLATION, AND THE DESIGN OF LIVING ARRANGEMENTS.

WE ARE AT A MODERN CROSSROADS TO RECONSTRUCT THE DEFINITION OF SERVICE CITIZENSHIP FOR OUR CONSTITUENTS. WE ARE AGAIN AT A POINT IN CALIFORNIA, AND, NATIONALLY, TO ESTABLISH A PERSPECTIVE CONSISTENT WITH OUR UNDERSTANDING OF MEANINGFUL GENERAL CITIZENSHIP. REPRESENTING THE APPROVAL OF THE DEPARTMENTS OF HEALTH, REHABILITATION, AND EDUCATION, AND THEREBY THIS ADMINISTRATION, WE ASSERT THAT THE CONCEPT OF DEVELOPMENTAL DISABILITY MUST BE RECOGNIZED AS A TEMPORARY SOCIAL SITUATION WHOSE RESOLUTION ENTIRELY RESTS WITH OUR COLLECTIVE ABILITY TO APPLY RESOURCES, KNOWLEDGE, AND PEOPLE IN ORDER TO TEACH, SHAPE, NURTURE, AND OVERCOME SPECIAL NEEDS THAT MAY EXIST IN RELATION TO AN INDIVIDUAL'S FUNCTION AND PERFORMANCE IN SOCIETY. IT IS THE QUALITY AND COMMITMENT OF OUR SERVICE SYSTEM THAT DETERMINES THE DEGREE OF EMANCIPATION FROM DISABILITY.

THE DEFINITION OF A DEVELOPMENTAL DISABILITY MUST EMBRACE THOSE CONDITIONS THAT INTERFERE WITH, OR INTERRUPT, TYPICAL DEVELOPMENT DURING THE PERIOD OF MOST CRUCIAL GROWTH OF THE HUMAN BEING, THAT IS, THE PERIOD BETWEEN BIRTH AND EIGHTEEN YEARS OF AGE, TO CONFINE THE NOTION OF A DEVELOPMENTAL DISABILITY TO A NARROW GROUP OF DIAGNOSTIC CATEGORIES IMPLIES THAT THOSE CHILDREN AND YOUTH DO NOT

SQUARELY FALL WITHIN ONE OF THESE LABELS, DOES NOT HAVE A DEVELOPMENTAL DISABILITY, THIS CONTRIBUTES TO THE SELF SERVING CONFINEMENT OF THE CONCEPT.

THE PIVOTAL ELIGIBILITY QUESTION REVOLVES AROUND THE NOTION OF SUBSTANTIAL HANDICAP. MANY YOUNGSTERS MAY HAVE A DEVELOPMENTAL DISABILITY BUT WILL NOT REQUIRE THE KIND OF COMPLEX AND ELEGANT ASSISTANCE OR ENVIRONMENTAL MANIPULATION FROM REGIONAL CENTERS. THIS RECOMMENDED DEFINITION, WHICH WE ARE SUBMITTING FOR SUBSTANTIAL HANDICAP, REQUIRES THAT A PERSON HAVE A DISABILITY WHICH OCCURS WITHIN THE FIRST EIGHTEEN YEARS OF LIFE, ESSENTIALLY AS DESCRIBED IN THE CALIFORNIA STATUTES. IN ADDITION HE/SHE MUST MEET A NUMBER OF CONCURRENT CRITERIA ALL OF WHICH MUST COEXIST. THESE CRITERIA HAVE BEEN DESIGNED TO DO TWO THINGS: FIRST, TO AS MUCH AS POSSIBLE DESTIGMATIZE THE PERSON BY IDENTIFYING THOSE AREAS OF HUMAN PERFORMANCE WHERE A DEFICIT OR SPECIAL NEED FOR SERVICES EXISTS. SECOND, TO DEFINE SUBSTANTIAL HANDICAP IN TERMS OF A SPECIAL SET OF NEEDED SERVICE CONDITIONS WHOSE ABSENCE CONSTITUTES A SUBSTANTIAL HANDICAP TO THE INDIVIDUAL IN ACTUAL SOCIAL TERMS, THESE DEMAND THE EXERIOSE OF GOOD JUDGMENT AND A KEEN ADVOCACY SENSITIVITY ON THE PART OF THE PROFESSIONAL REGIONAL CENTER EVALUATION STAFF,

IN STUDYING THE SITUATION, IT BECOMES APPARENT THAT AN INDIVIDUAL MAY HAVE SIGNIFICANT PERFORMANCE DEFICITS AND SPECIAL NEEDS AND BECAUSE OF A NUMBER OF ENVIRONMENTAL AND FAMILY ASSETS, ESSENTIALLY NOT REQUIRE REGIONAL CENTER SERVICES. ALTERNATIVELY, AN INDIVIDUAL WITH RELATIVELY MINOR DIFFICULTIES MAY FIND AN ENORMOUS SET OF BARRIERS TO OVERCOMING THE IMPACT OF HIS/HER CONDITION. IT IS CERTAINLY THE HOPE OF THIS DEPARTMENT THAT THE REGIONAL CENTERS

OR OTHER AGENCIES RESPONSIBLE FOR GROWTH AND HABILITATION SERVICES WILL DISCHARGE THEIR RESPONSIBILITIES IN SUCH A WAY THAT ONGOING INTERVENTION IN THE LIVES OF OUR CITIZENS WITH DEVELOPMENTAL SPECIAL NEEDS BECOMES LESS AND LESS NECESSARY AS SERVICES ARE RENDERED,

A SERIOUS CONCERN HAS BEEN VOICED BY A NUMBER OF RESPONSIBLE REPRESENTATIVES OF THE SERVICE AND CONSUMER COMMUNITIES THAT THIS FUNCTIONAL ELIGIBILITY DEFINITION WILL, "OPEN THE FLOODGATES" FOR EVERY PERSON THAT THE EDUCATION DEPARTMENT, OR WELFARE DEPARTMENT, WILL NOT, OR CANNOT SERVE, THESE CONCERNED VOICES FEAR THAT SUCH AN ATTITUDE WILL RESULT IN PEOPLE BEING WASHED TO THE REGIONAL CENTER DOORSTEP, THE PROTEST THAT THE FRAGILE BALANCE, CURRENTLY BEGINNING TO EXIST WITH THE REGIONAL CENTERS IN REGARD TO ELIMINATING WAITING LISTS AND COPING WITH THE STRINGENT TIMELINE OBLIGATIONS SET FORTH IN LAW TO COMPLETE DIAGNOSIS AND CASE WORK UP, WILL BE SHATTERED. IN RESPONSE, WE MUST SAY THAT PRIORITIES, BASED ON ANNUALLY CHANGING RESOURCE LIMITS, MAY BE REQUIRED FOR SOME TIME TO COME. THIS IS THE CASE REGARDLESS OF THE CRITERIA USED FOR ELIGIBILITY. AS HAS BEEN OUR MOST CURRENT EXPERIENCE, SUCH A NORMATIVE AND GENERIC CLIENT ELIGIBILITY DESCRIPTION WILL PROVIDE THE OBJECTIVE BASIS FOR APPROPRIATE BUDGET ALLOCATIONS EACH YEAR TO MEET POSSIBLE INCREASES IN NEED.

ANOTHER CONCERN HAS BEEN RAISED THAT TOO MUCH RESPONSIBILITY AND DISCRETION IS PLACED IN THE HANDS OF THE PROFESSIONAL WHERE THE CONSUMER WILL FIND HIM/HERSELF AT GREATER RISK OF BEING MANIPULATED AND EXCLUDED FROM RIGHTFUL SERVICES. IF THE POSSIBILITY OF ABUSES

EXIST, DUE PROCESS MECHANISMS ARE ESSENTIAL AND FEASIBLE TO ESTABLISH.

ADMITTEDLY, THE CONCISE LANGUAGE OF THE REGULATION WILL NOT SUFFICE TO PROVIDE THE POPULAR EXPLANATION TO CONSUMERS TO ASSURE THAT THEY UNDERSTAND THE LIMITS OF REGIONAL CENTER RESPONSIBILITIES. MOREOVER, THE REGULATORY DEFINITION WILL HAVE TO BE ARRANGED IN SUCH A WAY TO HELP MAKE A DECISION TREE TO ASSIST IN THE ELIGIBILITY DEFINING PROCESS. THESE REPRESENT ORIENTATION AND TRAINING CHALLENGES WHICH WE ACCEPT AND WILL ADDRESS.

IN SUM, EVEN THOUGH THIS PROPOSED DEFINITION MAY INITIALLY BE DIFFICULT AND NEW FOR MANY PEOPLE, IT CAN PROVIDE A MORE JUST BASIS FOR SERVICE ELIGIBILITY. IT WILL SIGNIFICANTLY CHANGE THE - EMPHASIS AND THE PERSPECTIVE OF THE DEVELOPMENTAL SERVICE SYSTEM STAFF TO BEGIN LOOKING AT THE PROGRAM NEEDS AND SURRENDER THE PRACTICE OF STIGMATIZING AND HABITUAL CLIENT LABELING. THE KEY IS TO SEPARATE THE PRINCIPLE AND STRATEGIC GOAL FROM PRACTICAL OR OPERATIONAL CONSIDERATIONS WHICH WILL REQUIRE WORKING OUT ONCE THE VALUE IS DECLARED.

THE DEPARTMENT OFFERS THESE DEFINITIONS OF DEVELOPMENTAL DISABILITY AND SUBSTANTIAL HANDICAP FOR YOUR CAREFUL CONSIDERATION AND REQUESTS YOUR PUBLIC ACKNOWLEDGEMENT OF THE PRINCIPLES AND ASSUMPTIONS THAT WE HAVE TRIED TO BUILD INTO THESE PROPOSED REGULATIONS.